or to manipulation. It may be thus suggested that, attempts to affect real change in the quality of the lives of families with handicapped children, may require some previously untried, perhaps unconventional strategies, aimed toward strengthening aspects of the situation that have not been approached in the past.

Dow's study of parents of 58 disabled children with mostly orthepedic disabilities yielded positive results. He found that "Parents everwhelmingly manifested optimism or a positive attitude toward the concept and actuality of disability. The majority of parents optimistically evaluated the implications of the child's disability, and the reaction of others to this, and expressed willingness to 'expose' the child. In contact with neighbors, friends, the public they felt no shame." 220

Holt, in an article which specified very clearly the wide range of problems found in families with retarded children, concluded by pointing out "that there were families who managed very well and showed emotional and spiritual reserves that suggested outside help would be superfluous." He describes some of the features that appeared to be associated with a positive adjustment, "The families who managed best were not those in the upper social classes. These parents were usually ambitious for their children and never overcame their frustration and disappointment. The ideal parents were those who, while sufficiently intelligent to appreciate the needs of the child and to have some insight into his difficulties

did not have great ambitions, and so they did not constantly display their disappointment." He also found that "Those families were better adjusted who had not concentrated all their hopes and desires upon one child and who had other things to think about, often other problems, so that the defective child was not forever in their minds."<sup>222</sup>

Dorner also found that some families with handicapped children made a positive adjustment to the situation, due to particular characteristics of these families. "It cannot be concluded, however, that a poor quality of life is inevitable in such circumstances (having a child with a severe physical handicap) since there were a number of families, who, because of the resilience of some or all of the members, the supportiveness of the marriage, and so on, had made a good adjustment to the problem of the handicap."223 Because of the nature of the characteristics which appear to facilitate a good adjustment, however, he points out that it is difficult to determine in advance which families these would be.

Fabrega and Haka also describe parental characteristics as determining the reaction to handicap. They found that the amount of disruption experienced depended not on the degree of the child's retardation, but on the parents' emotional resources. "Emotionally well-balanced parents could adapt to and accept their retarded children more easily than emotionally-driven, grieving parents, so preoccupied with the liabilities and stigma that they are not responsible to the needs of the child."224 Cohen, discussing the



impact of the handicapped child on the family, points out that "how a particular family makes its own adjustment is related to its customary pattern of meeting stress." 225

Bradshaw and Lawton, investigating stress in mothers of a handicapped child also indicate the importance of parental characteristics. They were surprised to find that variables such as degree of child's handicap, mobility of child, etc. did not make for variation in stress score. Having found unexpectedly few external factors that determined level of stress, they proposed an alternative hypothesis; that the level of stress is determined by internal factors - by the physiology and personality of the mother - and that these internal factors are not affected in any specific way by the external social and physical conditions of the family and the child. 226

Howell indicates his "tremendous respect for those families who are able to cope successfully" with the raising of a handicapped child. He postulates that these families have several factors in common: 1) The relationship of mother and maternal grandparents is especially important to the mencal health of the handicapped child's family. 227 2) A strong marital relationship - if this alliance is strong, the presence of the handicapped child may bind husband and wife closer, if weak, it may be dissolved by stress. 3) The order of the handicapped child in the sibship and the opportunity for successful parenting of normal children. 4) Presence of adequate, competent, and trusted professional care.



- 5) A listening professional ear as well as understanding friends.
- 6) Recreation and a change of pace and activity. 7) Ability to plan ahead relative to household management so that an unexpected event doesn't disrupt family living. 8) Helpful to live near services. 9) Deep sense of religious faith. 10) Opportunities to help others and the ability to help other parents usually represents a reasonably comfortable stage of adjustment. 228

#### VI. Some Additional Comments

## A. Selected Insights into the Literature

## 1) Interpretation of Research Findings

Implicit in the question, "What are the effects seen in families with handicapped children" is the added proviso, "because they contain a handicapped child". That is, what is really desired is a determination of the effects that are seen because the family includes a handicapped member, that would not exist if it didn't. The difficulty is, in this respect, as Hannan indicates:

At times, it is difficult to distinguish the problems of 'normal' child-rearing from those specifically related to mentally-handicapped children. All children get on their parents' nerves, they all make messes and they all need and demand more attention than most adults can normally give them. 229

Families with only normal children have difficulties, are subjected to stresses and strains and are affected in various ways by the presence of their children. Some families with normal children cope better than others; some may exhibit extreme reactions such as the break-up of the marriage, parents depressions, etc. The question then becomes, do these negative aspects occur in families with handicapped children to an extent that is greater than that in families with only normal children? Answering such a question requires studies that are carefully controlled, that can



compare the incidence found in families of the handicapped with that of families of normal children, or of that found in the general population. Many of the studies described above, did not have such controls, but rather pointed out that a particular effect, or problem, was found in a certain percentage of the families with handicapped children under study. Interpretation of the results of such studies must, therefore be carried out with the utmost care, keeping in mind the intrinsic limitations of such results. They cannot be used as evidence that the presence of the handicapped child "causes" certain effects.

## 2) The Difference between Families with a Handicapped Child and Those with Only Normal Children

Although the state of the art, thus, does not permit an authoritative delineation of the effects that are <u>due</u> to the presence of a handicapped child, some insight can be gained from the literature as to differences between the families, that might make for differences in effects seen. That is, in reading a large amount of material on families with handicapped children, the differences between these families, and those with only normal children, began to be formulated. These differences, both quantitative and qualitative, would be presumed to be the factors that would be the basis for differences in family functioning, and in the impact that raising a child is seen to have on the



family members. The following suggestions as to these differences are an attempt to share some initial insights gained. As this was not considered to be an original goal of this discussion, it should not be considered a comprehensive, or systemic, presentation.

The differences between these families and those with only normal children appear to be both quantitative and qualitative. In terms of quantitative differences, it sometimes appears, in reading the literature, that should a family with only normal children have their child care responsibilities multiplied a thousandfold, they would have some feeling of what raising a handicapped child may entail. That is, like families with normal children, there are responsibilities that families with handicapped children must undertake; they get up at night to care for their children, prepare special foods when necessary, care for their children when ill, deal with incontinence, supervise children who can't be left on their own, etc. However, these child care responsibilities of the families of the handicapped appear to be greater in two ways. First, they often go on for many more years, sometimes a great many more years. Parents of the handicapped may have to be carrying out these same responsibilities for years after their counterparts with normal children have been able to stop worrying about getting up at night, incontinence, constant supervision and so on. Second, the responsibilities can be more intense; illnesses may be very frequent and lifethreatening, supervision may have to be almost 24 hours a day.



There are also qualitative differences in the care that is entailed; elements that are involved because the child is handicapped, that are not seen in families with only normal children. Especially for the parents of physically handicapped, care may involve a whole sphere beyond that provided by parents of normal children, and require the mastering of equipment that these parents would never see; wheelchairs, braces, shunts, etc.

It also appears that qualitative differences in the emotional underlay of these families lives can be very great. The whole experience of having a child may be stigmatized when that child is handicapped; the way in which he is regarded, by society, and by his parents may be different from that of a normal child, and many aspects of his life be viewed in a different light. Thought of the child's future, may be especially troubling, when a child is handicapped, raising worrisome doubts, rather than hopeful thoughts of possible achievements.

# 3) Differences Between the Families of the Mentally and the Physically Handicapped

Some impressions were also gained, in reading through the literature, on a number of differences between those families with mentally retarded, and those with physically handicapped, children. There were a number of particular differences in emphasis that stood out when reviewing the literature in regards to specific



aspects. Once again, there is no attempt to present a systematic or comprehensive discussion of this issue, but rather to describe a rumber of points that became clear.

It appears that, with retardation, because of the mental limitations of the child, parents may have more of a sense of the "line of the future" being disturbed, that the child doesn't carry on the family name and tradition. This aspect was not mentioned in regard to parents of the physically handicapped. Also, there may be no speech, and, if brain damage is involved, bicarre behavior, so that communication with the child may be impaired to a greater extent than in those families with a physically handicapped child. An orientation towards the child as a "normal child with a handicap" may be more difficult for parents of retarded.

with physical handicap, the illness may be progressive and the condition of the child a constant cause of concern.

Numerous hospitalizations may be involved to a greater extent than when the handicap is mental. Getting around with the child may be difficult, and involve constant lifting and the use of special equipment, For those children with normal intelligence level, the philosophical meaning of being handicapped may have to be dealt with. The self-awareness of oneself as handicapped ap ears to be more developed in the physically handicapped than in the mentally retarded. The physically handicapped child may



share in an understanding of the stigma with which society imbues his position, and be aware of the reaction of strangers to a greater extent. Parents may, accordingly, have to deal with his reality-based depression to a greater degree than would parents of mentally handicapped.

### B. The Interrelationship of Effects

#### 1) A Hypothetical Model

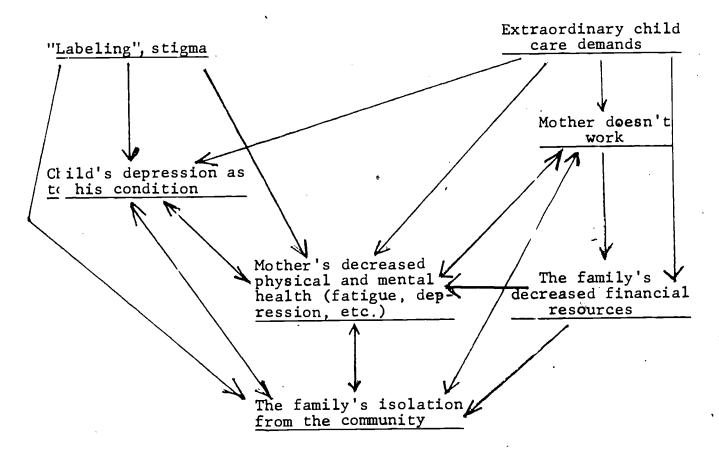
In discussing the literature on the effects on the family of having a handicapped child, each effect was discussed individually, as a separate aspect of the impact seen. However, in reality, it appears that the effects described interact with one another. That is, not only, for example, is a mothers' health affected by the presence of a handicapped child, but also, the state of her health contributes to other effects seen, her husband's mental health, the family's relationship to the outside community, etc. In this way, the effects described effect one another in a complicated pattern of interactions.

In attempting to fully understand the impact on the family of living with a handicapped child, it might be useful to attempt to trace this possible interaction of effects so that a feeling for the dynamics involved might be gained. To this end, a diagrammed presentation will be included below, which represents speculation as to how a number of effects described in the literature might interact. As no research as to this is in evidence,



this conception is speculative in nature. Each of the effects included in the diagram has been mentioned in the literature; the relations tips described between them are hypothetical. The effects don't necessarily interact as is described, but they may do so.

## Model of the Interrelationship of Effects





#### 2) Explanation of the Relationships Shown in the Model

Two independent variables, the extraordinary child care demands of the handicapped child, and the "labling" and stigma associated with having a handicapped child, are seen as leading to the other effects. The first of these variables is seen as directly contributing to 4 effects: the mother's decreased physical and mental health, the mother's not working, the family's decreased financial resources, and the child's depression as to his condition. These effects, in turn, interact with one another. The mother's not working adversely affects her mental health, and the worse her mental and physical health, the more likely she is not to work. Not working also has a negative effect on the family's financial resources, which is likely to further worsen her mental health. The stigma associated with having a handicapped child contributes to depression in both the child himself, and in the mother, and each of these is likely to affect the other. stigma involved, the child's depression, the mother's mental and physical state, the fact that the mother doesn't work, and the family's decreased financial resources are all seen as likely contributors to the family's isolation from the community. This, in turn, is seen as a factor further affecting the mother's and the child's, mental health.

It can thus be seen that, even with only a few of the possible effects considered, the picture begins to be very complex; with



effects contributing to other effects, in a complicated pattern of interactions. It also becomes clear how a family might become involved in a negative cycle; as a number of aspects begin to go badly, others follow, until the family may find itself in a very bad situation, from which it is difficult to excricate itself.

## 3) Use of the Model in Program-Planning

In considering interventions aimed at improving the lot of the family with a handicapped child, recourse to such a model may be of use. Understanding the interactions between variables would allow for conceptualization of the projected outcomes of potential programs. The expected, or optimal, effects of a program directed toward a specific goal could be traced. For example, should an information campaign to educate the public about handicap and so, lessen the social stigma, be considered the influence that this could be expected to have on the families of the handicapped could be formulated (i.e. decreased depression in mother and child, decreased isolation from the community; each of which could be expected to lead to other changes in the configuration of factors).

Also, reference to such a model would permit identification of those factors that play a key role in determining the family's situation; those which, if successfully manipulated, would be expected to effect the greatest change, by influencing the largest number of variables. Programs aimed at such key variables would, thus, have the greatest likelihood of improving the family's condition.



In terms of this hypothetical model, for example, the predominance of the mother's physical and mental health status is clear. Should this status be improved, and the mother not be depressed, the whole outlook changes as the influence on other variables is felt. She might then work, which would help the family finances and further improve her mental health, the family would tend to be less isolated from the community, and the child himself would feel better about his situation. A systematic consideration of the interaction of factors, as set forth in this hypothetical model, is thus suggested as a potential aid to rational program-planning.



#### VII. Notes

- 1. The lack of material on handicapped offsprings as adults within the family may reflect a number of factors. The number of adult handicapped living with their families may be small, due to death or institutionalization. This may also reflect the choice of subject by the researchers, who may find families with handicapped children a more accessible, dramatic or fundable focus of investigation.
- See model in final section, for a suggestion as to an alternateway to establish the importance of a various effect; the degree to which it effects other aspects of family functioning.
- 3. It is considered fruitless to enter into a discussion as to whether, a mother's depression, for example, is more likely attributable to her dismay at having produced an imperfect child, or to the considerable work his care involves. The goal therefore would be to indicate the existence of both these elements, and to cite them as factors likely playing a part in her low spirits.
- 4. Holt, K.S., 1958a, "The Home Care of Severely Retarded Children", Pediatrics 22, 4, 1, 744-55, p. 750.
- 5. Kew, Stephen, 1975, <u>Handicap and Family Crisis</u>, London: Pitman, p. 159.



- 6. Ibid.
- 7. McMichael, Joan K., 1971, <u>Handicap: A Study of Physically Handicapped Children and their Families</u>, London: Staples Press, p. 76.
- 8. Birenbaum, Arnold, 1971, "On Managing a Courtesy Stigma", J. of Health and Social Beh., 11:3, pp. 196-206, p. 196.
- 9. Wolfensberger, Wolf, and Menolascino, Frank J., 1970, "A Theoretical Framework for the Management of Parents of the Mentally Retarded", in Menolascino, Frank J., ed. <u>Psychiatric Approaches to Mental Retardation</u>, New York: Basic Books, p. 475.
- 10. Ibid.
- 11. Ibid., p. 477.
- 12. This section is based on Ryckman, David B., and Henderson,
  Robert A., 1965, "The Meaning of a Retarded Child for his
  Parents: A Focus for Counselors", Mental Retardation (August)
  pp. 4-7.
- 13. Wolfensberger, Wolf, 1968, "Counseling the Parents of the Retarded", in Baumeister, Alfred A., ed., Mental Retardation:

  Appraisal, Education and Rehabilitation, Chicago: Aldine Publishing Company, pp. 329-300, p. 332.



- 14. It may be noted that the literature upon which this section is based, refers only to the mentally retarded. It might be that, for example, physically handicapped children of normal intelligence do not involve the same reappraisal of parental feelings and aspirations. In the absence of research findings, it might be interesting to speculate upon factors that might influence this; degree of handicap, presence or absence of bizarre symptology, level of intelligence, parental attitudes towards the dysfunction involved. It appears possible that a wide range may exist in regards to the meaning to parents of having a handicapped child, from only a slight reappraisal of expectations and goals, to feelings that no normal expectations can be made in regards to the child.
- 15. McMichael, op. cit., p. 78.
- 16. Ibid., p. 77.
- 17. It is clear that this is a relationship that goes both ways; the family's emotional reaction will help to determine the child's. See final section for a discussion of the interaction of factors.
- 18. McMichael, op. cit., p. 78.
- 19. Ibid., p. 56.



- 20. Kolin, I.S., et al, 1971, "Studies of the school-age child with meningomyelocele: Social and emotional adaptation", J. of Pediatrics, 78:6 (June), pp. 1013-9, p. 1018.
- 21. Minde, Klaus, et al., 1972, "How They Grow Up: 41 Physically Handicapped Children and Their Families", Amer. J. Psychiat., 128:12 (June), pp. 104-109, p. 107.
- 22. Ibid., p. 108.
- Dorner, S., 1975, "The Relationship of Physical Handicap to Stress in Families with an Adolescent with Spina Bifida", Develop. Med. Child. Neur., 17, pp. 765-776, p. 769.
- 24. Ibid., p. 769.
- 25. Wolfensberger and Menolascino, op. cit., p. 476.
- 26. Anderson, Elizabeth and Spain, Bernie, 1977, The Child with Spina Bifida, London: Methuen, p. 72.
- 27. Kew, op. cit., p. 158.
- 28. Ibid.
- 29. Hannam, Charles, 1975, <u>Parents and Mentally Handicapped Children</u>, Harmondsworth: Penguin Books, p. 73.
- Howell, S.E., 1973, "Psychiatric Aspects of Rehabilitation", Pediatric Clinics of North America, 20, 203, p. 205.



- 31. Holt, op. cit., p. 746.
- 32. Ibid.
- 33. Ibid.
- 34. Mercer, Jane R., 1966, "Patterns of Family Crisis Related to Reacceptance of the Retardate", Amer. J. Men. Def., 71, pp. 19-32, p. 26.
- 35. Ibid., p. 27.
- 3ε. Ibid., p. 29.
- 37. Hannam, op. cit., p. 73.
- 38. Ibid.
- 39. Ehlers, W.H., 1966, Mothers of Retarded Children: How They Feel, Springfield: Charles C. Thomas, p. 23.
- 40. Barsch, Ray H., 1968, The Parent of the Handicapped Child, Springfield: Charles C. Thomas, p. 355.
- 41. Begab, Michael J., 1966, "The Mentally Retarded and the Family", in Philips, Irving, ed. Prevention and Treatment of Mental Retardation, New York: Basic Books, pp. 71-84, p. 76.
- 42. Ibid., p. 77.
- 43. Ibid., p. 78.

- 44. Holt, op. cit., p. 746.
- 45. Richards, I.D. and McIntosh, H.T., 1973, "Spina Bifida Survivors and Their Parents: A Study of Problems and Services"

  Devel. Med. Child Neur., 15, 292-304, p. 297.
- 46. Bradshaw, J. and Lawton, D., 1978, "Tracing the Causes of Stress in Families with Handicapped Children", Br. J. Soc. Wk., 8:2, pp. 181-191, p. 187.
- 47. Begab, op. cit., p. 78.
- 48. Ibid., p. 80.
- 49. Freeston, B.M., 1971, "An Enquiry into the Effect of a Spina Bifida Child Upon Family Life", <u>Devel. Med. Child Neur.</u>, 13, pp. 456-61.
- 50. Drotar, D. et al, 1975, "The adaptation of parents to the birth of an infant with a congenital malformation", <u>Pediatrics</u>, 56, pp. 710-717, p. 715.
- 51. MacKeith, Ronald, 1973, "The Feelings and Behaviour of Parents of Handicapped Children", <u>Devel. Med. Child Neur.</u>, 15, pp. 524-527, p. 526.
- 52. McMichael, op. cit., p. 87.
- 53. Ibid., p. 89.



- 54. Ibid., p. 113.
- 55. Anderson and Spain, op. cit., p. 69.
- 56. Ibid.
- 57. Wolfensberger and Menolascino, op. cit., p. 476.
- 56. Wolfensberger, op. cit., p. 330-335.
- 50. Wolfensberger, op. cit., p. 331.
- 60. Cohen, Pauline C., 1962, "The Impact of the Handicapped Child on the Family", Soc. Casework, XLIII: 3 (Mar.), pp. 137-142, p. 138-9.
- 61. Drotar et al, op. cit., 711-2.
- 62. Wolfensberger, op. cit., p. 347.
- 63. Ibid., p. 334.
- 64. Willner, S.K., and Crane, R., 1979, "A Parental Dilemma: The Child with a Marginal Handicap", Soc. Casework 60:1 (Jan.), pp. 30-35, p. 32.
- 65. Wolfensberger, op. cit., p. 334.
- 66. Ibid.
- 67. Ibid.
- 68. Ibid., p. 335.



- 69. Holt, op. cit., p. 747.
- 70. Ibid.
- 71 Ibid., p. 748.
- 72. The Carnegie United Kingdom Trust, 1964, <u>Handicapped Children</u> and Their Families, Edinburgh: T & A Constable Ltd., p. 73.
- 73 Ibid., p. 78.
- 74 Ibid., p. 260.
- 75. Howell, op. cit., p. 205.
- 76. Ibid.
- 77. Ibid.
- 78. Walker, J.H. et al, 1971, "Spina Bifida and the Parents",

  Dev. Med. Child Neur., 13, p. 462-75, p. 470.
- 79. McMichael, op. cit., p. 90.
- 80. Ibid., p. 122.
- 81. Ibid., p. 123.
- 82. Ibid., p. 124.
- 83. Dorner, op. cit., p. 772.
- 84. Ibid.

- 85. Erickson, Marilyn, 1969, 'MMPI Profiles of Parents of Young Retarded Children', Amer. J. Men. Def., 73: 5 (Mar.), p. 728 ff, p. 730.
- 86. Tew, Brian, and Laurence, K.M., 1973, "Mothers, Brothers and Sisters of Patients with Spina Bifida", <u>Dev. Med. Child Neur</u>., Supplement 29, 15: 6, p. 69-75, p. 74.
- 87. Ibid.
- 88. Bradshaw and Lawton, op. cit., p. 183.
- 89. Ibid.
- .90. Ibid., p. 189.
- 91. Cummings, S.T. et al, 1966, "Effects of the Child's Deficiency on the Mother: A Study of Mothers of Mentally Retarded, Chronically Ill and Neurotic Children", Amer. J. Orthopsy., 36, p. 595-605, p. 595.
- 92. Ibid., p. 605.
- 93. Ibid.
- 94. Love, H.D., 1970, Parental Attitudes Toward Exceptional Children, Springfield: Charles C. Thomas, p. 29.
- 95. Cummings, S.T. et al, 1976, "The Impact of the Child's Deficiency on the Father: A Study of Mentally Retarded and Chronically Ill Children", Am. J. Orthopsy., 46: (April), pp. 245-255, p. 251.



- 96. Ibid., p. 252.
- 97. Ibid., p. 253.
- 98. Ibid., p. 253.
- 99 Waisbren, S.E., 1980, "Parents' Reactions after the Birth of a Developmentally Disabled Child, Amer. J. Men. Def., 84: 4, pp. 345-351, p. 348.
- 10C. Ibid.
- 101. Ibid.
- 102. Gath, Ann, 1977, "The Impact of an Abnormal Child Upon the Parents", Brit. J. Psychiat., 130, pp. 405-10, p. 408.
- 103. It is of interest that these two studies, which did make provisions for comparison with mothers of normal children, both led the researchers to conclude that differences were not significant. However, a number of points should be considered. The samples are relatively small, especially in the Waisbren study where couples differed not only on the mental status of their children but also on country of residence. Also, both studies focused on very joung children, with a maximum age of two years. It is possible that mental strain of parents with retarded child is more noticeably different from that of parents with normal children at older ages for a number of reasons; behavior differences between



retarded and normal may be more striking in older children and the demands of child rearing of normal children in early ages may be so great that mental health of parents tends to be at a low point. Also, as neither study indicated the intelligence level of the retarded children, the severity of the retardation may have been less than in other studies described.

- 104. Mandelbaum, A. and Wheeler, M.M., 1960, "The Meaning of a Defective Child to Parents", Soc. Casework, XLI: 7 (July), pp. 360-367, p. 362.
- 105. Barsch, op. cit., p. 349.
- 106. Ibid.
- 107. Drotar et al, op. cit., p. 716.
- 108. Holt, op. cit., p. 749.
- 109. Ibid., p. 750.
- 110. Gath, op. cit., p. 408-9.
- 111. Ibid., p. 409.
- 112. Ibid.
- 113. As it was not possible to gain access to this book, the comments of two reviewers, quoted below, were used.



- 114. Sinson, Janice, 1979, "Review of Gath, Ann, Down's Syndrome and the Family: The Early Years, London: Academic Press, 1978", Brit. J. Men. Subnor., No. 48, (June), p. 50.
- 115. Oswin, Maureen, 1979, title as above, <u>Devel. Med. Child Neur.</u>, 21: 3 (June), pp. 406-7.
- 116. Pillig, Doria, 1973, The Handicapped Child: Research Review, Vol. III, London: Longman Group Ltd., p. 41.
- 117. Ibid.
- 118. Ibid.
- Social Consequences, Boston: Houghton Mifflin, p. 162.
- 120. Pillig, op. cit., p. 41.
- 121. Ibid., p. 42.
- 122. McMichael, op. cit., p. 89.
- 123. Ibid., p. 122.
- 124. Ibid., p. 113.
- 125. Walker, op. cit., p. 470.
- 126. Freeston, op. cit , p. 458.

- 127. Dorner, op. cit, p. 772.
- 128. Tew et al, 1974, "Must a Family with a Handicapped Child be a Handicapped Family?" Devel. Med. Child Neur., 16: 6, Supple. No. 32, pp. 95-98, p. 95.
- 129. Ibid., p. 96.
- 130. Ibid., p. 97.
  - 131. Ibid.; p. 97.
  - 132. Kolin et al., op. cit., p. 1017
  - 133. Ibid.
- 134. Martin, Patricia, 1975, "Marital Breakdown in Families of Patients with Spina Bifida Cystica", Devel. Med. Child Neur., 17, pp. 757-764, p. 761.
  - 135. Ibid.
  - 136. Kew, pop. cit., p. 51.
  - 137. The Carnegie United Kingdom Trust, op. cit., p. 79.
  - 138. Tizard and Grad, cited by Farber, op. cit., p. 160.
  - 139. Mandelbaum and Wheeler, op. cit., p. 363.
  - 140. Barsch, op. cit., p. 200.

- 141. Kolin et al, op. cit., p. 1017.
- 142. McMichael, op. cit., p. 116.
- 143. Holt, K.S., 1958b, "The Influence of a retarded child upon family limitation", J. Men. Def. Res., 2, 28-34.
- 144. Holt, 1958a, op. cit., p. 748.
- 145. Tizard, and Grad, cited by Pillig, op. cit., p. 37.
- 146. The Carnegie United Kingdom Trust, or . cit., p. 79.
- 147. Begab, op. cit., p. 76.
- 148 Kew, op. cit., p. 52.
- 149. Richards and McIntosh, op. cit., p. 297.
- 150 McMichael, op. cit., p. 64.
- 151. Farber, op. cit., p. 163.
- 152. Farber, op. cit., p. 165.
- 153. Richards and McIntosh, op. cit., p. 297.
- 154. Tizard and Grad, cited in Pillig, op. cit., p. 37.
- 155 The Carnegie United Kingdom Trust, op. cit., p. 79.
- 156. Farber, op. cit., p. 160.

- 157. Wolfensberger, op. cit., p. 346.
- 158. Kew, op. cit., p. 58.
- 159. Bradshaw and Lawton, p. 185.
- 160. Holt, 19:8a, op. cit., p. 747.
- 161. Kew, op. cit., p. 52.
- 162. Barsch, op. cit., p. 350.
- 163. Meyerowitz and Kaplan, cited by Farber, op. cit., p. 161.

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- 164. Howell, op. cit., p. 205.
- 165. Farber, op. cit., p. 160.
- 166. Ibid.
- 167. Ibid., p. 161.
- 168. Kew, op. cit., p. 61.
- 169. Ibid., p. 62.
- 170. Ibid.
- 17... Ibid., p. 63.
- 172. Walker, op. cit., p. 470.
- 173. McMichael, op. cit., p. 69.

- 174. Ibid., p. 70.
- 175. Holt, 1958a, op. cit., p. 748.
- 176. Ibid., p. 750.
- 177. Dorner, op. cit., p. 772.
- 178. Barsch, op. cit., p. 343.
- The importance of control groups, of parents of normal children, becomes clear in considering an issue such as this one. That is; even if it is asserted that it is not the presence of the handicapped child that leads to isolation of the family, but rather their attitude towards joining in community activities, it has yet to be shown that isolationist attitudes are not more common among families with a handicapped child. i.e. Is the percent of "joiners", and that of "loners" the same for families with handicapped and normal children?
- 180. Bradshaw and Lawton, op. cit., p. 186.
- 181. This concept can be compared to Farber's postulation of "home oriented" families as one of three theoretical types of family organization developed by parents of a retarded child. In such families "parents are seen as completely sacrificing their life chances for family cohesion" (Farber, op. cit., p. 165).



- 182. Schaffer, H.R., 1964, "The 'Too-cohesive' family: A form of group pathology", Inter. J. Soc. Psych., 10, p. 266.
- 183. Tew et al, op. cit., p. 96.
- 184. McMichael, op. cit., p. 62.
- 185. Ibid., p. 70.
- 186. Ibid., p. 71.
- 187. Holt, 1958a, op. cit., p. 748.
- 188. Plaza Hotel, 12/6/80.
- 189. Bradshaw and Lawton, op. cit., p. 186.
- 190. McMichael, op. cit., p. 102.
- 191. Ibid., p. 127.
- 192. Richards, op. cit., p. 297.
- 193. Tew and Laurence, op. cit., p. 74.
- `194. Pillig, op. cit., p. 46.
  - 195. Ibid.
  - 196. Holt, 1958a, op. cit., p. 747.
  - 197. Ibid., p. 750.

- 198. Ibid., p. 747.
- 199. Barsch, op. cit., p. 348.
- 200. Wolfensberger, op. cit., p. 341.
- 201. Pillig, op. cit., p. 46.
- 202. Farber, op. cit., p. 164.
- 203. Pillig, op. cit., p. 47.
- 204. Farber, op. cit., p. 154.
- 205. Ibid.
- 206. Ibid.
- 207. Ibid., p. 155.
- 208. Farber's theory that SES determines the crisis that the family experiences, does not appear to have been tested empirically. It is perhaps, a somewhat extreme view of the situation. It may be more likely that both types of considerations play a part in the crisis for all families. That is, all families with a handicapped child would be expected to have to deal with both the philosophical meaning of having a handicapped child, and the practical problems of care child and reorganization of daily life that are entailed. It may be true that families in different SES groups focus more on one aspect



of the crisis than the other, but it is difficult to believe that both aspects don't have to be considered. Also, empirical testing of such a hypothesis may be difficult. Should it be found that families in the lower SES groups do seem to focus more on the practical problems of organizing daily life to accomodate a retarded child, than those in the higher SES group, this might be as well explained by the fact that their limited resources make the practical problems more difficult to solve, as by an assertion that it is due to their investing the label of retardation with a different meaning.

- 209. Ehlers, op. cit., p. 41.
- 210. Ibid., p. 43.
- 211. Farber, op. cit., p. 156.
- 212. Cummings et al, 1969, op. cit., p. 603.
- 213. Zuk, cited by Wolfensberger, op. cit., p. 344.
- 214. Kolin, op. cit., p. 1017.
- 215. Wolfensberger, op. cit., p. 346.
- 216. Mowatt, Marian, 1970, "Group Therapy Approach to Emotional conflicts of the Mentally Retarded and their Parents", in Menolascino, Frank J. ed., <u>Psychiatric Approaches to Mental</u> Retardation, New York: Basic Books, p. 422.



- 217. Dow, T.E. 1966, "Optimism, Physique and Social Class in Reaction to Disability", <u>J. Health Hum. Beh</u>., 7: 1, pp. 14-19, p. 16.
- 218. Ibid.
- 219. Bradshaw and Lawton, op. cit., p. 185.
- 220. Dow, op. cit., p. 15.
- 221. Holt, 1958a, op. cit., p. 753.
- 222. Ibid., p. 754.
- 223. Dorner, op. cit., p. 773.
- 224. Fabrega, H. and Haka, K.H., 1967, "Parents of mentally handicapped children", Arch. Gen. Psych., 16, pp. 202-9, p. 207.
- 225. Cohen, op. cit., p. 138.
- 226. Bradshaw and Lawton, op. cit., p. 189.
- This tends to support Farber's assertion
  that"when the parents of a retarded child are in frequent
  contact with the wife's mother, marital integration tended
  to be high...Ordinarily the wife's mother showed much sympathy
  and understanding for her daughter's situation." (op. cit., p. 162)
- 228. Howell, op. cit., p. 205.
- 229. Hannam, op. cit., p. 73.

